

## **CONNECTICUT LEGAL RIGHTS PROJECT**

---

Box 351, Silver Street, Middletown, CT 06457  
Telephone (860) 262-5030 • Fax (860) 262-5035

**TESTIMONY OF KARYL LEE HALL, ESQ.  
of the Connecticut Legal Rights Project  
in Support of Raised Bill No. 368,  
An Act Concerning the Health Information Technology  
Exchange of Connecticut.  
March 16, 2012**

On behalf of the Connecticut Legal Rights Project, Inc. ("CLRP"), I am writing to express our support for Raised Bill No.368. Our organization is a statewide non-profit agency that provides free legal services to low income adults with psychiatric disabilities. Our clients often have lengthy medical records that include sensitive behavioral health, substance abuse and HIV information in addition to other health information. Much of this information is protected except when individuals expressly release the information in a written document which specifies the records to be released, to whom the record is to be released and for what length of time the release will be effective. While we are supportive of advances in health information exchange, we are unwilling to support a system that does not clearly recognize the right of each individual to participate at the start by making a decision to opt-in to the exchange. For that reason, we support Raised Bill no. 368 which requires every patient to supply an advance authorization to the electronic health information system before any information is released.

1. MANY AGENCIES AND PROGRAMS WORK WITHIN A PERSON CENTERED MODEL THAT WOULD BE AT ODDS WITH A SYSTEM THAT DOES NOT REQUIRE AN AFFIRMATIVE ACT BY THE PATIENT TO RELEASE HIS OR HER MEDICAL RECORD.

As the Centers for Medicare & Medicaid Services ("CMS") has recently stated: "The person-centered approach is a process, directed by the individual . . ." Federal Register, Vol. 76, No. 73, April 15, 2011, at 21313. Likewise, services provided by the Department of Mental Health and Addiction ("DMHAS") are "consumer driven." Practice Guidelines for Recovery-Oriented Care for Mental Health and Substance Use Conditions, Services DMHAS, Second Edition (2008) at 8. These and other new policy developments, such as the Department of Social Service's new model for Medicare/Medicaid eligibles and the Person-centered Medical Home Initiative are changing the focus of service delivery and treatment to a more individualized approach that emphasizes patient preference. To be consistent, the Health Information Technology Exchange must likewise recognize that primary decisionmaking is in the hands of the person whose

information is to be exchanged. That person must be informed about what data will be shared, with whom, and what consequences will follow from the exchange. With the appropriate advance information, the effected individuals can then make their own decision about participation in the system. It is essential that this occur before the information is exchanged so as to reflect the primacy of individual decisionmaking.

2. A SYSTEM THAT REQUIRES A PATIENT TO OPT OUT PLACES AN UNDUE BURDEN ON THE PROVIDER TO FILTER INFORMATION THAT WOULD REMAIN PROTECTED ABSENT A RELEASE FROM THE PERSON CONTROLLING ACCESS TO THE RECORD.

We recognize that under the Health Information System certain behavioral health and substance abuse data would not be shared, even in an opt-out system, unless the person provided a release. This falls far short of adequate protection for the consumer and would be a burden for the provider. It has been publicly stated by medical practitioners at the Advisory Committee on Privacy and Security (and it is widely acknowledged) that sensitive information is often released inadvertently by providers because the line between protected information and information that is not protected is confusing and uncertain. Thus, an opt-out system arguably puts a patient's information at risk well before he or she has made the decision to incur it. Furthermore, providers sensitive to liability issues under HIPPA will spend valuable time trying to distinguish one class of information from another. The requirement that there be a release on file that covers both kinds of information at the start of the exchange and is freely proffered by the individual will be a protection to that individual's privacy rights but also will be a protection for the provider trying to successfully use the health information exchange for the benefit of the patient.

For these reasons, we urge you to support Raised Bill No. 368.